

Sheryl Silver, founder/president
Johanna's Law Alliance for Women's Cancer Awareness
Email: Sgsilver2002@yahoo.com
Sheryl@johannaslaw.org
Media Contact: 954 647 5995

Testimony for Sheryl Silver

September 7, 2005 Hearing on Women and Cancer:

"Where Are We in Prevention, Early Detection and Treatment of Gynecologic Cancers?"

I'd like to thank the subcommittee for this opportunity and focus on the urgency of the need to create a national program of education to improve early detection of gynecologic cancers in the U.S.

As the person who first proposed Johanna's Law, legislation that would create a national program of gynecologic cancer education, I feel a responsibility to sound an alarm today, to make sure this subcommittee and anyone reading or hearing my testimony knows that we have a national tragedy that needs to be addressed. Unlike the national tragedies that have thankfully taken place only once in our history – like the tragedy of Sept 11th and the tragic devastation we have just witnessed from Hurricane Katrina, the national tragedy I'm referring to has been going on for years and years and years.

This national tragedy relates to the thousands and thousands of women lost each year in this country to gynecologic cancers. In the last 10 years alone, we have lost over 250,000 American women to these cancers. In just the last 4 years, since the tragic events of 9/11, we have lost over 100,000 American mothers, sisters and daughters on domestic soil---not from terrorist attacks, thank God --- but just as tragically, from gynecologic cancers. In the nearly 3 years since I proposed Johanna's Law, legislation that would create a national program of gynecologic cancers, we have lost 75,000 American women --- 25 times the number of Americans lost on 9/11 --- in less than 3 years.

And what magnifies the tragedy of all these deaths is the fact that they are not inevitable. A diagnosis does not have to be a death sentence. Diagnosed at the earliest stage, ovarian, uterine and cervical cancer---which account for over 90 percent of all new diagnoses in the U.S. each year--- these 3 cancers all have 5-year survival rates greater than 90 percent, with women diagnosed early commonly going on to live normal, healthy lives for many years.

And yet, tens of thousands of women in this country each year are diagnosed after their cancer has progressed beyond the earliest and most survivable stage. The problem is particularly common with ovarian cancer, which is diagnosed approximately 80 percent of the time at stages that are much less survivable. Contributing to these late stage diagnoses is a lack of knowledge about the symptoms of the disease that commonly leads to lengthy delays in diagnosis. My sister Johanna was a victim of this life-threatening information gap.

We were stunned when Johanna was diagnosed with advanced ovarian cancer. We had no family history of the disease. What's more, my sister was a vigorously healthy and health conscious

woman who visited the gynecologist regularly for recommended pelvic exams and Pap smears. She ate nutritiously, exercised regularly. She did everything she knew of to live a long, healthy life. Unfortunately, the one thing she didn't know was that persistent bloating and heartburn were two of the common symptoms of ovarian cancer.

When she began to experience these symptoms, she assumed they were due to a minor gastric problem. She took antacids. When the symptoms persisted, she made an appointment to see a gastroenterologist and waited patiently several weeks for that first appointment, never thinking the delay might be life-threatening.

By the time Johanna saw her gynecologist and the appropriate diagnostic studies were performed, she was scheduled for major surgery a few days later. That surgery confirmed the shocking diagnosis of advanced ovarian cancer.

Although Johanna's doctor initially predicted she had just 12 –18 months to live, with aggressive treatment that included 4 surgeries, endless rounds of chemotherapy and participation in two clinical trials, my determined and courageous sister survived 3 ½ years. She was, however, rarely in remission and lived the last 8 months of her life tethered to an IV pole 12 hours a day for her basic hydration and nutrition --- and eventually 24 ours a day for the pain medication that dulled her agony. This was a horrible way for a loving, dynamic and health conscious daughter of a doctor to lose her life. Yes, my dad was a physician. So is my brother and yet we were as stunned by Johanna's diagnosis as every other family impacted by this disease that I've met in the 8 years since my sister's diagnosis.

That's why I proposed Johanna's Law --- not because my sister was one unlucky, uninformed daughter of a doctor but because her story is tragically common. In the days after Johanna's diagnosis, nearly every woman friend and family member we told about her situation was shocked ---not only to learn that their vigorously healthy friend had been diagnosed but that the gastric symptoms she'd had were common symptoms of ovarian cancer. They hadn't known it.

Neither had the ovarian cancer survivors I met in Johanna's support group at Gilda's Club or at national conferences on ovarian cancer I started attending the year Johanna had her first recurrence. Woman after woman had nearly identical stories. Nearly all had been diagnosed at advanced stages of ovarian cancer. All but one HAD LEARNED ONLY AFTER BEING DIAGNOSED that the symptoms they had experienced for months were common symptoms of the disease. And sadly, when their doctors attributed their symptoms to benign conditions with similar symptoms, without first ordering the appropriate diagnostic studies to detect ovarian cancer, since these women had no idea their symptoms could be due to ovarian cancer, they couldn't even say to their doctors: "Shouldn't we first rule out the most lethal cause of these symptoms, ovarian cancer, before assuming something benign is the problem?"

This is the deadly status quo Johanna's Law is designed to address. By providing women information about the symptoms and risk factors of gynecologic cancers, the program of gynecologic cancer education it would create can empower women experiencing symptoms to recognize them as potentially dangerous, prompting them to seek appropriate medical attention quickly and ask questions that ensure a gynecologic cancer is considered among the possible causes during a first visit, not months later as has so often occurred.

This problem is not new. I've heard stories of women who went through the same terrible experience decades before Johanna's diagnosis. And I hear about the same problem occurring today --- nearly 9 years after my sister was diagnosed and five years since she died. Commonly I hear of women who had symptoms and searched for answers for months before they were diagnosed, and who died within 1 - 5 years of being diagnosed with late stage ovarian cancer, despite multiple surgeries and aggressive chemotherapy regimens.

The needless suffering and deaths resulting from women not knowing the symptoms of ovarian cancer has gone on too long --- and cost too many precious American lives. And frankly, it's about time this national tragedy was adequately addressed and the source of it eliminated.

As President Bush said last Friday during on-camera remarks about Hurricane Katrina, "The job of the federal government is to save lives because every life is precious."

I absolutely agree with the president on that point. Every life is precious --- and just as we know that responding quickly with adequate resources can spare needless suffering and death following hurricanes and other natural disasters, we who have advocated for Johanna's Law believe that we can similarly spare more American families needless suffering and death by creating and funding a program of gynecologic cancer education.

We know that women, given the right information, will seek appropriate and complete medical attention sooner. Had my sister Johanna known that she possessed risk factors for ovarian cancer --- which she did --- or that she was experiencing common symptoms of the disease, she would have rushed to see her gynecologist and made sure the right diagnostic studies were performed. Every ovarian cancer survivor I've ever met would have done the same had she known that her symptoms could have been related to this deadly disease, which kills more women in the U.S. each year than all other gynecologic cancers combined.

But none of these women ever had the chance to take the actions that might have led to earlier detection and their long-term survival. None of them had the chance because none of them ever got the information about symptoms until after they were diagnosed at a late stage when even aggressive treatment couldn't save most of their lives.

My sister had planned to be around to watch her daughter marry and have children. She looked forward to being a grandmother and to being there to help our aging parents in their later years. And again, my sister was not alone in having such dreams and goals.

And yet my sister and hundreds of thousands of wonderful women in this country have been robbed of all those precious moments. Their families have been robbed of all those memories with them because their loved ones died decades before they should have simply because we lack better tools for earlier detection of this cancer and because they learned about the symptoms of this cancer too late to take advantage of existing diagnostic tools.

This is a national tragedy that has gone on for decades --- but we have a chance right now, this year, to stop it. The thousands of family members and survivors across the country who have contacted their legislators, many for the first time in their lives, have asked them to co-sponsor Johanna's Law in hopes of sparing other American families the terrible nightmare we have all lived through. The program of education we are hoping to create can't spare our families this agony. It can, however,

give us a small measure of healing to know that our loved ones have not suffered or died in vain but that our federal government has heard our pleas --- and responded quickly, compassionately, and appropriately --- to create the national program of gynecologic cancer education this nation has so long needed.

Let it be part of the legacy of the 109th Congress that this Congress created this long overdue program --- and that along with addressing homeland security, natural disasters and other challenges our country faces --- let it also be known that this Congress acted this month, during Gynecologic Cancer Awareness Month, to spare more American families the needless suffering that comes with a late stage diagnosis of ovarian and other gynecologic cancers.

We may not save every life with a program of education, but we can save more than we have been and we can give women a fighting chance to be detected in time for their lives to be saved.

As a compassionate nation known for valuing every one of its citizens, we must do all we can --- as quickly as we can --- to improve early detection. That means that while we wait for research breakthroughs which we desperately need and hope will bring us vaccines and even better tools for early detection and treatment of late stage cancers, while we wait, the one thing we can do now, this month, is create a national program of gynecologic cancer education.

Just last week, we saw how quickly the House moved to provide the funding needed to help the families devastated by Hurricane Katrina. **We know this Congress can move quickly whenever it deems a particular issue or situation a crisis or top priority. I am here today to say that this situation, too, must be considered a top priority, a national tragedy that has gone on for years --- quietly, desperately, in hospices, hospitals and homes.** And even though these tragedies are not seen on our television screens, the agony endured by families impacted by late stage gynecologic cancers is excruciating. There is terror and desperation for every one of us as we helplessly watched those we love run out of medical options and then die.

I apologize if these comments offend anyone who hears or reads them. I am merely trying to express the magnitude of the agony felt by all of us who have supported our courageous loved ones through their battles with ovarian cancer and then helplessly watched them die.

We want to spare the millions of American women at risk for gynecologic cancers --- and their families -- this same excruciating agony. The members of the 109th Congress can help us achieve that goal by creating a national program of gynecologic cancer education and awareness. Besides saving lives through early detection, such a program will finally give a measure of peace to millions of grieving family members. It will assure us that our loved ones did not suffer and die in vain but rather, that their stories served as the catalyst for creating America's long overdue --- but urgently needed --- national program of gynecologic cancer awareness and education

I thank the Subcommittee for its patience in listening to the pleas of a grieving sister.